



Standardised Data on Initiatives - STARDIT

Jack S Nunn^{1*}, Thomas Shafee², Steven Chang³, Richard Stephens⁴, Jim Elliot⁵, Sandy Oliver⁶, Denny John⁷, Maureen Smith⁸, Neil Orr⁹

¹School of Psychology and Public Health, La Trobe University, Victoria, Australia

²School of Life Sciences, La Trobe University, Victoria, Australia

³La Trobe University, Victoria, Australia

⁴Patient Representative for Genomics England Access Review Committee

⁵Public Involvement Lead at Health Research Authority (England)

⁶Professor of Public Policy at UCL Institute of Education

⁷Evidence Synthesis Specialist, Campbell South Asia

⁸Cochrane Consumer Executive Co-chair

⁹Senior Policy Analyst, Evaluation and Research, Centre for Epidemiology and Evidence, NSW Ministry of Health

20 Plain English summary

21 This document outlines a proposal for a standardised way of describing the ‘who’, ‘how’ and ‘what’
22 of initiatives such as research, education interventions, policy and international development. It will
23 create a way to share **Standardised Data on Initiatives** – or STARDIT for short.

24 STARDIT is a proposed way of developing terminology to report ‘interventions’, ‘research’, ‘projects’
25 and other similar words that describe any kind of ‘initiative’ or action, standardising data about
26 initiatives and reporting impacts in multiple human languages.

27 STARDIT is designed to create a standard way to share information about who was involved in an
28 initiative (who did which tasks), what was done, what was learned and any impacts which occurred.
29 It is designed to be useful across all disciplines, including health, environment, basic science, policy
30 and international development. STARDIT reports will be shared open access (in the public domain),
31 using machine readable linked-data.

32 STARDIT also provides a way for initiatives to share ongoing updates to create ‘living’ reports
33 throughout the lifetime of an initiative (for example, at the planning stage, the doing stage and the
34 evaluation stage). Data is structured to facilitate machine translation. In this way STARDIT will help
35 contribute to creating novel metrics for future research, across languages.

36
37 Experts will inform how data will be shared in a way which will allow anyone to analyse the data.
38 This will facilitate the creation of “living-systematic reviews” which could compare initiatives,
39 including impacts and methods of involvement - allowing future involvement in research to be more
40 evidence-informed.

41
42 STARDIT is being co-created in a collaborative way, with anyone in the world invited to be a part of
43 shaping the development. All information about it will be shared for free under a Creative Commons
44 licence.

45 The project is currently being hosted by the WikiJournals on Wikimedia Foundation servers. The co-
46 creation process is being supported pro-bono by the charity ‘Science for All’ and has received in kind
47 support from the EPPI-Centre.

48

49 Abstract

50 Ensuring people affected by initiatives (including research, education and international
51 development) are involved in shaping how they are done is essential to ensure that what is being
52 done (including what is being researched) is aligned with the priorities of those affected. This
53 includes ensuring that access to knowledge generated from the initiative is universal (open access),
54 according to the UN Convention of Human Rights¹.

55 Meanwhile, 'citizen science' and participatory action research are blurring the lines between
56 concepts such as 'researcher', 'public', 'patient' and 'citizen'. For example, those researching global
57 air pollution are not limited to distinct disciplines such as 'public health', 'environment' or
58 'education', with everyone affected, including researchers. The importance of involving people in
59 initiatives by sharing power is clear, but evidence-informed methods of doing this are lacking.

60 Creating an evidence base to inform the most effective ways of sharing power when designing, doing
61 and evaluating initiatives is essential in order to ensure efficient, effective and equitable ways of
62 working for the benefit of all.

63 **Standardised Data on Initiatives (STARDIT)** is designed to create a standard way to share information
64 about who was involved in an initiative (who did which tasks), what was done, what was learned and
65 any impacts which occurred. It is designed to be useful across all disciplines, including health,
66 environment, basic science, policy and international development. STARDIT reports will be shared
67 open access (in the public domain), using machine readable linked-data.

68 STARDIT is being co-created in a collaborative way, with anyone in the world invited to be a part of
69 shaping the development. All information about it will be shared for free under a Creative Commons
70 licence. The project is currently being hosted by the WikiJournals on Wikimedia Foundation servers.
71 The co-creation process is being supported pro-bono by the charity 'Science for All'.

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73 Introduction

74 Background

75 The United Nations (UN) Universal Declaration of Human Rights states that everyone has the right to
76 'receive and impart information'¹. The UN also states that 'democracy, development and respect for
77 all human rights and fundamental freedoms are interdependent and mutually reinforcing'². To
78 uphold human rights and for 'the maintenance of peace', people require 'media freedom' in order to
79 'seek, receive and impart information'².

80 Never has it been more important to support people to be able to be involved in accessing, creating,
81 and appraising information about reality, in order to make informed, fact-based decisions³. The
82 scientific method is the best model humanity has currently to understand reality, sometimes by
83 observing the effects of interventions (things we have done). In some contexts we call this research,
84 in other contexts it is 'evaluation', 'international development', 'education' or an 'initiative'.
85 Hereafter all of the above will be referred to as an 'initiative'.

86 Organisations such as Cochrane and the Campbell Collaboration have been working for decades to
87 create trusted and high-quality systematic reviews to help understand medical, social and economic
88 interventions; but there is much more to be done both in these disciplines and many others in order
89 to create an evidence base for informing the choice and implementation of initiatives.

90 Where we do initiatives (including choosing what gets researched) and where we do not do them
91 has enormous implications for what humanity can know⁴. Those with different interests or stakes
92 (stakeholders) may have financial or other interests, and may have perverse incentives to shape
93 future initiatives in ways which compete or conflict with complex concepts such as 'public interest'⁵.
94 For example, a systematic review found that industry funded research is more likely to have
95 outcomes favouring the sponsor⁶. Similarly, the well-documented influence of the tobacco industry
96 on the research agenda is a relatively simple example of the complex and profound problems with
97 how human knowledge is created and shared by those with 'power'⁴.

98 Ensuring people affected by initiatives are involved in shaping how they are done is essential to
99 ensure that what is being done (including what is being researched) is aligned with the priorities of
100 those affected⁷. This includes ensuring that access to knowledge generated from the initiative is
101 universal (open access), according to the UN Convention of Human Rights¹.

102 Meanwhile, 'citizen science' and participatory action research are blurring the lines between
103 concepts such as 'researcher', 'public', 'patient' and 'citizen'^{8,9}. For example, those doing the
104 initiative and those affected by it may be the same people. The importance of involving people in
105 initiatives by sharing power is clear¹⁰, but evidence-informed methods of doing this are lacking⁸.

106 In addition, many of the problems facing humanity, such as air pollution, are not limited to distinct
107 disciplines such as 'public health', 'environment' or 'education'. The approach to solving these
108 problems requires complex and holistic 'systems thinking'¹¹. Concepts such as national borders and
109 'intellectual property' may begin to increasingly compete or conflict with solutions to inter-
110 jurisdictional problems such as influenza pandemics and air pollution³. This in turn requires a form of
111 reporting data from initiatives that is consistent across disciplines, including reporting data on how
112 people were involved.

113 Governments, charities, research organisations, publishers, indigenous peoples, and industries
114 around the world are increasingly required to work in partnership with other global citizens to solve

problems and create positive opportunities. For example, the future of genomic research and genomic initiatives is challenging how we collect, analyse and share ‘big data’¹², with decisions about this potentially affecting all life on earth. Creating an evidence base to inform the most effective ways of sharing power when designing, doing and evaluating initiatives is essential in order to ensure efficient, effective and equitable ways of working for the benefit of all⁸.

This paper proposes a model for the continued improvement and refinement of the processes, language and taxonomies associated with involving people in planning initiatives, doing them and then reporting who was involved in which tasks and how. It is a task-based approach, promoting the use of the scientific method where possible.

Standardised Data on Initiatives (STARDIT) is being created in partnership with a number of experts and organisations, including the Wikimedia Foundation, a global leader in both refining and improving multi-lingual and international ways of sharing knowledge. Other partners include researchers from La Trobe University, the not-for-profit organisation ‘Science for All’, Campbell South Asia, Health Research Authority (England), members of the Cochrane Advocacy Advisory Group, the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), the Poche Centre for Indigenous Health (Sydney University), UCL Centre for Co-production in Health Research.

STARDIT is intended to provide a helpful working model for comparison⁸, with any linguistic terms co-created by those involved and mapped to a universal taxonomy of linked-data, facilitating both machine translation and automated integration into future living-systematic reviews (see section ‘Defining concepts in universal taxonomy’).

Objective

To create a working version of a data-sharing platform that will provide a number of solutions to address the problems of inconsistency in sharing data about initiatives (including all kinds of research) and who has been involved in the initiative and how. This framework is intended to support a culture of partnership working across disciplines (in science, publishing, government, education and international development). Where possible STARDIT has been designed to align with existing models and frameworks which are specific to certain areas and disciplines.

Potential impacts and outcomes

Novel metrics will be co-created using both qualitative and quantitative outcome measures. This will be made available in the public domain, and can be used for assessing impacts of both the initiatives themselves and impacts from involving different stakeholders in that initiative. The term ‘stakeholder’ is used here to mean anyone who has a ‘stake’ in an initiative, in particular those who have important knowledge, expertise or views that should be taken into account^{13,14}. This would increase the evidence-base and support informed decision making when planning involvement in initiatives.

STARDIT will be developed in partnership with anyone who would like to be involved, and will initially be adopted by the Wikimedia Foundations open-access peer reviewed journals. If it is adopted by a ‘critical mass’ of other publishers, research funders and governments, it could create a novel ‘prestige’ within research and development communities to use the reporting framework.

Over time, if successful, publishers and research funders could then move to a model which requires all initiatives to use this framework, allowing those accessing research to appraise public domain

records of who was involved in which aspects of the research; how people were involved; how was data shared and any impacts from the research.

Definitions

This reporting framework takes a participatory action research paradigm to all actions. The linguistic separation between concepts such as ‘intervention’, ‘research’, ‘project’, ‘initiative’ and other similar terms is not as important as articulating ‘aims of specified action’, ‘who did which tasks or actions’ and ‘outcomes from specific action’.

In this way, STARDIT can be helpful for reporting any kind of intervention, project or initiative. For example, while it may be a helpful framework for reporting basic lab research or a clinical study, it may be just as useful for reporting an educational intervention in a community.

This paper will use the word ‘initiative’ to describe any intervention, research or planned project. Examples include a:

- **Research project** – any organised activity undertaken to answer a question. This includes data collection and analysis to help answer future questions which may arise. Projects may be nested within one another – the report context should clarify this
- **Project or initiative** - any organised activity undertaken with planned outputs or outcomes.
- **Educational intervention** – any organised activity designed to improve people’s knowledge, understanding or skills^{15,16}
- **Evaluation** – an attempt to evaluate an action or phenomena, including related impacts and outcomes. This includes program or policy evaluation

The concept of “involvement” in is defined as when research, initiatives or medical interventions are carried out “with” people rather than “on” them¹⁷. Involvement can also be defined as when power is shared, in order to allow the public, citizens, communities, patients or research participants to actively contribute to the process of research, an initiative, intervention or policy development¹⁸. Involvement is also distinct from engagement, which is when information and knowledge about is shared with the public¹⁹.

Defining concepts in universal taxonomy

The terms used in this paper are working terms, and will be standardised as far as possible as this project continues. These terms will then be mapped to a universal taxonomy. One proposed method for doing this is to work within the unified semantic and grammatical framework established by the Wikimedia Foundation’s Wikidata initiative. This initiative includes standardised definitions, relationships between concepts and translations. Using this will allow translation from and to other languages (for example, a numerical code describes certain colours in the spectrum which can then be translated into multiple languages). This will also aid machine learning, analysis by neural networks and other forms of artificial intelligence (AI), similar to the ‘Cochrane Crowd’ project²⁰.

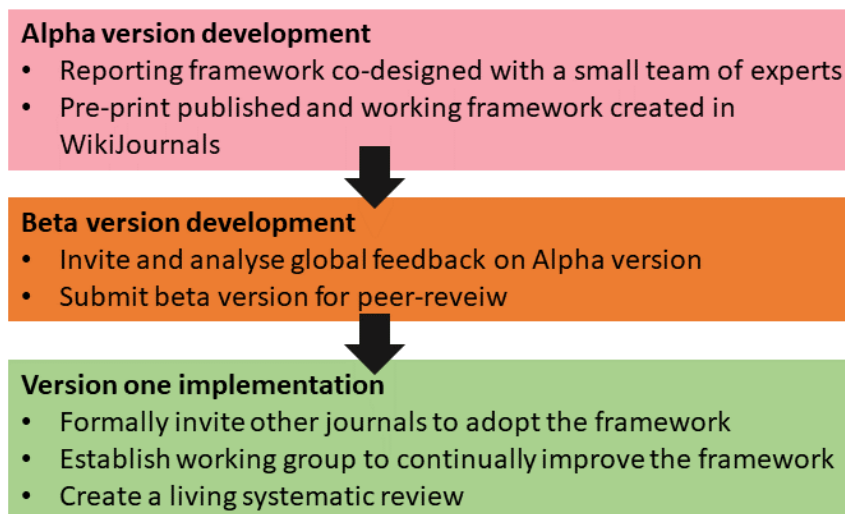
Those involved in developing this framework can then work to group certain concepts and code them, aligned as far as possible with existing taxonomies, such as the National Library of Medicine’s Medical Subject Headings²¹. For example terms like ‘research participant’, ‘patient’ and ‘principal investigator’ have clear and easily defined descriptions which are assigned codes. This will be an ongoing process and may require creating a tool which allows for an evolving taxonomy. For example, the Wikidata entry for ‘patient’ defines it as a ‘person who takes a medical treatment or is

subject of a case study²². The entry is assigned a code and has been automatically translated into 54 other languages. Similarly, the Wikidata entry for 'phase 1 clinical trial' indicates that it is performed on 20-100 healthy people, in order to determine 'safety and dosage' but not efficacy²³.

STARDIT development phases

In order to be effective, it is essential that STARDIT involves as many people as possible, receiving input and ideas from people from a diverse range of disciplines and backgrounds. This section describes the development process so far, and the planned next stages and project governance. Figure X summarises this process.

Figure 1: STARDIT development



Alpha version development method

- This pre-print was created with a small team of experts from a number of different disciplines, informed by their work with diverse communities around the world.
- The initial alpha version was informed by a number of frameworks and models (see supplementary materials [‘Models which inform the standardised reporting framework’](#))
- Draft versions were shared with co-authors and final decisions were made using an online decision making platform, hosted pro-bono by the not-for-profit organisation ‘Science for All’, working in partnership with the Wikimedia Journals.
- This process was used to create this pre-print, and a working alpha version in the WikiJournals.
- The team co-created a method to invite feedback and improvement from as many people as possible in the proposed beta development.

Proposed Beta version development

- Co-create method for involving people in developing STARDIT, informed by EQUATOR method for developing reporting guidelines and other relevant guidelines.
- Invite public feedback on pre-print. A link to the paper and the feedback form will be shared widely in the public domain and via networks.

- Public events will be held in the UK and Australia, with people able to join online. The events will invite feedback and open-ended discussion.
- Decisions will be made using an online decision making platform, hosted pro-bono by the not-for-profit organisation 'Science for All'²⁴, working in partnership with the Wikimedia Journals.
- Submit beta version for peer-review in appropriate journals

Version one implementation

- Formally invite other journals to adopt the framework, as well as other appropriate partner organisations such as the UN and WHO
- Establish working group to continually improve the framework in order to align with as many international models as possible, including taxonomy development
- It is proposed the working group will be co-hosted by the not-for-profit organisation 'Science for All', although co-designing a tender process may be necessary for future versions.

Cultural neutrality during implementation

Certain cultural values, assumptions, ways of thinking, knowing or outcome measures may not be shared universally. The participatory process involved in creating a project such as STARDIT requires that it attempts to map these, rather than unconsciously reinforce particular (and often 'dominant'²⁵) cultural values. STARDIT must be implemented in a way which encourages those involved to acknowledge cultural values and assumptions in a transparent way. For example, people with human-centred (anthropocentric) thinking, which values natural resources in relation to benefits they can provide for humans is in contrast to people who think the value of nature should be measured using non-human outcomes (ecocentric)²⁶.

Many problems facing humans are shared by non-human life-forms and eco-systems, for example, rapid climate change. With eco-systems like rivers and non-human animals now being assigned 'personhood'^{27,28}, post-colonial environmental and social sciences have attempted to challenge and redefine traditional and colonial-era concepts of what can be 'owned' as property⁵. In order for initiatives, research and other interventions to operate in an inclusive, culturally neutral way it is necessary to lead a reconsideration of the language to describe the relationship between humans and the environment at a personal, national and international level⁵. For example, a public consultation by the 'dominant' people or cultures in a society might ask 'who owns the rights to a water in a river system?'²⁵. This might presume the dominant people's values of 'owning' a natural resource are universally accepted by all of the public they wish to consult, thus imposing their values on people who might not share the concept of 'ownership'. For example, Western European legal and economic traditions might be incompatible with those of some indigenous peoples^{5,29,30}.

By working in partnership from the start of the process, the STARDIT project is an attempt to map this process and provide both guidance for planning and evaluating involvement in initiatives. However it will be an ongoing and complicated process to 'de-colonialise' language and a challenge to some people's cultural attitudes which may not align with the universally enshrined principles of democracy, human rights and environmental rights.

268 Logo

269 A logo will be required for STARDIT in order for it to be recognised, including one which does not
270 contain letters. The proposed logos are below. Figure 2 is the proposed full STARDIT logo, figure 3 is
271 the proposed icon. Logos

272 Figure 2: Full logo



273

274 Figure 3: Icon



275

276 Creating evidence with living systematic reviews

277 A number of reviews have called for standardised ways of reporting involvement in research over
278 extended periods of time in order to improve evidence-informed ways of involving people, and to
279 understand 'works, for whom, why, and in what circumstances' ^{8,10,31}. Living systematic reviews of
280 STARDIT reports could create a useful evidence-base for informing future best-practice. The stages
281 would involve:

- 282 • Forming a team scope the feasibility of creating a living systematic review based on the data
- 283 from the reports (including exploring funding and partnership working)
- 284 • Work in partnership with relevant stakeholders to ensure it informs international best-
- 285 practice
- 286 • Agree which data can be included in living systematic review
- 287 • Agree long term governance of the process of creating reviews, working in partnership with
- 288 organisations such as Cochrane and the Campbell Collaboration

289 Scope and applications of STARDIT

290 STARDIT is the first data sharing platform to provide a standardised way of reporting how people are
291 involved in any initiative, across any discipline, including a framework for involving people in co-
292 designing the initiative.

293 This section addresses the current proposed scope and applications of the framework.

294 Table 1 summarises the current limitations of existing reporting frameworks and models, showing
295 the proposed solutions the STARDIT model offers.

Limitations of current models and frameworks	Solutions to current limitations proposed by this framework
<p>There are numerous models and reporting frameworks, which change according to the research discipline – making it difficult for governments and international organisations to assess impacts from interventions and creating challenges and for global change research³².</p> <p>The principles of involvement in research and other interventions are the same across all fields (health, environmental, basic, community based participatory, education), yet a significant number of models and frameworks are specific to health research. For example, existing models such as GRIPP2 are only appropriate for certain kinds of health and social care research³³. In addition, a recent systematic review concluded the GRIPP checklist has not been widely adopted within the health and social care literature as yet and that journals do not require authors to report in that format³⁴.</p> <p>Recent international consensus statements have clearly defined a role for the public in research which is ‘data intensive’, a kind of research which will continue to grow in importance³⁵. While such statements call for both an assessment of impact and an evaluation of the process, numerous studies call for the creation of a standardised framework to report involvement in this kind of research^{36–38}.</p>	<p>This framework creates a standardised way for reporting interventions that is consistent across all disciplines of research.</p> <p>This framework does not attempt to replace any other model or framework, but to ‘sit above’ them, complimenting and incorporating other frameworks when required.</p> <p>Journals can adopt the online reporting framework and research funders can require completion.</p>
<p>Most other models and frameworks require research authors to know about them and adopt that framework</p>	<p>Those reporting on initiatives are encouraged to adopt the reporting framework when submitting papers for publication (by trialling the framework with publishers and research funders). The framework is intended to create new metrics for research impact, which over time, will create an incentive for researchers to report involvement and impact. While initial motivation for reporting may be intrinsic, as more partner organisations (such as research funders) adopt the framework, there may be formal requirements to report, or a form of prestige associated with being able to report impacts.</p>

Some models and frameworks are behind paywalls³⁹, or remain ‘intellectual property’– and are not in the public domain to allow adaptation or continuous improvement.

The linguistic variation between terms such as ‘involvement’, ‘engagement’ and ‘participation’ makes objective comparisons of interventions difficult. Concepts do not always easily translate to other languages, despite many research projects being multi-lingual in scope and impact.

Time delays mean that evaluating the impact of research after the project is difficult to achieve and difficult to disseminate ³⁹. A number of reviews have called for standardised ways of reporting involvement in research over extended periods of time in order to improve evidence-informed ways of involving people, and to understand ‘works, for whom, why, and in what circumstances’ ^{8,10,31}.

There is a potential power imbalance and bias in only having certain stakeholders write up research and assess the impacts (for example, only researchers, not research participants or research users).

There is often an unhelpful or unnecessary divide between labels like ‘researcher’, ‘participant’, ‘patient’ and ‘the public’ which are likely to become increasingly blurred – for example, in future citizen science projects and public health genomics ⁴¹.

The model will be licensed under Creative Commons – with the quality of any future iterations being the responsibility of not-for-profit host organisations.

The framework will use an ‘action-based’ approach to the spectrum of involvement ⁴⁰ – requiring clearly described ‘tasks’, negating a need for fixed definitions of concepts such as ‘involvement’, ‘engagement’ and ‘participation’. Where possible, terms and concepts will be mapped to a taxonomy which will allow translation between languages. The participatory model of the project means that anyone will be able to get involved in co-designing and co-defining terms use in the framework.

The reports are ‘living’ and can be updated over time, allowing impact from research projects to be captured after the project has completed. The ‘purpose’ or the ‘why’ of the initiative and the purpose of involving people in certain tasks can also be reported in a consistent way.

The reports will be hosted by the WikiJournal of Science and quality-control (checking citations) will be carried out by the Editors.

The reports will create an evidence-base for future living systematic reviews to analyse involvement and allow evidence informed involvement.

The reporting framework can be led by the authors of the research, and will encourage the inclusion of multiple stakeholders in order to define outcome measures, identify indicators and collect and interpret data ³². It will also provide an opportunity for people involved in the project to be authors of the STARDIT report.

The framework treats all with parity, encouraging self-identification to labels which people feel are most appropriate. Anyone can be listed as carrying out any task, regardless of their label.

Mapping preferences for involvement

Involving multiple stakeholders in designing how people are involved in initiatives is considered best practice and may facilitate involvement⁸. Figure X is a mock-up of the STARDIT Preference Mapping (STARDIT-PM) which uses the STARDIT reporting framework as a tool to map the views and perspectives of potential stakeholders about involvement.

It requires individuals to self-identify as belonging to a specific group of people (groups with specific co-created definitions), and share views about how other groups of people could be involved, or who should not be involved. For example, groups could include:

- **Only people with a professional role** in the initiative
- **Everyone** (any member of the public who is interested)
- **Anyone who might be indirectly affected** by the initiative
- **Only people who are directly affected** by the initiative
- **Only people who are participating** in the initiative
- **Only people with a financial interest** in the initiative

It may be necessary to co-create further groups and sub-groups.

By using a consistent tool across all initiatives, it allows a comparison of the views of different stakeholders, exploring similarities and variation about preferences for involvement.

This approach creates a workable and consistent way for future projects to explore views and perspectives of stakeholders in initiatives (for example, a research project). When used alongside other planning tools, it can be used to help plan initiatives according to the preferences of stakeholders. In this way, how stakeholders are involved throughout the initiative can be co-designed at the start.

Analysis of this data should involve a range of different stakeholders to ensure that a diversity of perspectives are involved in assigning meaning to any data.

The questions for mapping preferences are summarised below in Table 2.

Table 2: Questions for mapping preferences for involvement

Question	Rationale for question
Which stakeholder group does this person align with?	To establish which group the person identifies as being part of – for example ‘researcher’ or ‘participant’
Describe any financial relationship or other interest this person has to this project	To provide a public record of any potential conflicting or competing financial interest
Views on who should be involved (which ‘groups’ of people) – including who should not be involved	To establish that person’s views on which ‘groups’ of people they think should be ‘involved’ in research – that is, having a role in shaping the research design, direction and outcomes
Views on specific tasks of this person or group	To establish that person’s views on the tasks of the people who they think should be involved. <i>Note: Answers may require sub-categories if there are multiple categories for who should be involved (see Figure X</i>

Preferred modes of communication	To establish that person's preferences on communication modes
Views on what methods should be used	To establish that person's views on which methods should be used to involve people – for example 'online survey'
Views on facilitators of involvement	To explore that person's perceptions of what might facilitate involving specified groups of people and help inform the design of involvement
Views on barriers of involvement	To explore that person's perceptions of what might be a barrier to involving specified groups of people and help inform the design of involvement
Views on what the outcome or output of the involvement could be	To ascertain the expectations of that person about what involving the specified groups of people might achieve
Views on which stage of the research this group should be involved?	To establish that person's views on which stage of the research the specified groups of people should be involved in

325 Figure 4: Mock-up of the STARDIT Preference Mapping (STARDIT-PM)

326

Which stakeholder group does this person align with?	Describe any financial relationship or other interest this person has to this project	Views on who should be involved	Views on specific tasks of this person or group	Views on modes of communication	Views on what methods should be used	Views on facilitators of involvement	Views on barriers of involvement	Views on what the outcome or output of the involvement could be	Views on which stage of the research this group should be involved?
Researcher?	Employed by institution co-ordinating the research study	Hand-picked representatives from participants	Reviewing informed consent documents	Email, face to face	One-off meeting	Budget	Institutional resistance (people are against involvement)	Improved recruitment	Recruitment
		Researchers	All other aspects of research	Teleconferences	Informal meetings	Quiet working space	Limited time	Aligned with grant application requiring involvement	All
Participants	Expenses paid by institution co-ordinating the research study	Elected representatives	Over-see data access	Face to face, email	Formal committee with terms of reference	Culturally appropriate language	Not having a mix of face to face and telecoms	Improved ethical access to data	All stages
		General public	Overseeing ethics	Social media	Survey			Improved ethics governance	

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330 Standardised Reporting of Dissemination, Involvement and 331 Translation – Alpha Version

332 The data fields in the platform are summarised in the following tables. Table 3 is the full version of
333 the data fields. Table 4 is the Minimum Contribution Reporting Form (MICRO), which is shorter
334 version of this that contains the minimum information required to make a report.

335 Technical details

336 This report can be filled out as a simple online form. Some categories will have prescribed answers
337 which will be machine-readable as XML data.

338

339 While there must be named people accountable for the data in the reporting framework,
340 completion can be led anyone associated with the initiative, including employees, researchers,
341 participants or people affected by the initiative and other stakeholders. As many people as
342 practicable should be involved in completing the report, including defining outcome measures,
343 identifying indicators and collecting and interpret data³²

344

- 345 • Once this report is completed it generates a version number of the report, which will be
346 archived in the public domain (including Internet Archive) creating an immutable version. It
347 is all updatable. Any future updates will be reviewed/approved by editors (for quality
348 control) and when approved will generate new version numbers.
- 349 • This will allow ongoing updates about the research project, including information about
350 involvement, dissemination and translation over time, co-creating new metrics for
351 'impact'⁴².
- 352 • A short version of this reporting framework is the '**Minimum Contribution Reporting Form**'
353 (MICRO) which is the minimum information required to make a report. These fields are
354 coloured blue.

355

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358 Table 3: Standardised Reporting of Dissemination, Involvement and Translation –
 359 Alpha Version

Section	Data category	Data field
Initiative context - This information locates the initiative within a clear context.	Identifying information	Initiative name
		Geographic location or scope
		Date range (planned start and end dates of initiative)
		Purpose of the initiative
		Organisations or other initiatives involved (list all if multi-centre)
		Funding sources
		Clinical trial registration details (if applicable)
		Ethics approval (if applicable)
		Other relevant information (free text)
		Relevant URLs/URIs*
		Link: Description:
		Other relevant information (free text)
		RAiD (API)
	Stage or state of initiative	At which stage of the research project has this report been written? (Select from: 1. Before the intervention or initiative– this report is prospective or describes planned activity 2. Ongoing – the intervention or initiative is still taking place 3. After the research project or initiative has occurred
		Methods of the initiative (what is planned to be done, or is being reported as done)
Report authorship – Information about who completed the report and how	Identifying information for each author (authors can be anonymised in the public report but identities will need to be sent to WikiJournal Editors to attempt to prevent falsified reports)	Name
		Public domain profiles, institutional pages
		Open Researcher and Contributor ID (orcid.org)
		Tasks in report completion
		Other information
Involvement in initiative Who is involved in this initiative and how? Editors assessing involvement may need to use the STARDIT 'Indicators of involvement' tool	Accountability	Key contact at initiative for confirming report content
	Details about how each group or individual was involved in the initiative	Who was involved (select from groups or submit new group name in free-text)
		Specific tasks of this person or group (list as many as possible) – <i>including any information about why certain people were included or excluded in certain tasks</i>
		How were these people involved (what methods were used)
		Facilitators of involvement (what do you expect will help these people get involved – or what helped them get involved)

		Barriers of involvement (what do you expect will inhibit these people from getting involved – or what inhibited them from getting involved). Are there any known equity issues which may contribute?
	Outcomes and outputs	What was the outcome or output of the involvement of these people? What changed as a result of involving people?
	Stage	Which stage of the initiative were these people involved? (select from list of pre-defined stages or allow 'other')
	Cost and time	What was the estimated financial cost for involving people. How much time did it take. Were there any costs that cannot be measured financially?
	Learning points	What worked well, what could have been improved? Was anything learned from the process of involving these people?
Mapping financial or other 'interests'	Financial or other interests	Describe any financial relationship or other interest this person has to this project
		Describe any conflicting or competing interests
Research data	Hosting and storage	Who is the data from this intervention shared with?
		How is it stored and hosted?
	Analysis	Who is analysing the data?
		What methods will be used to analyse the data (including a link to any relevant code and information about validity)
	Dissemination	How is information about this data disseminated?
	Ownership and control	Who 'owns' the data or claims any kind of 'intellectual property' (include relevant licensing information)
		Who controls access to the data
	FAIR criteria ⁴³	How is/will the data be 'Findable, Accessible, Interoperable, Reusable' according to the FAIR criteria?
Research impacts	What was learned	What new knowledge has been generated? (if appropriate, include effect size, relevant statistics and level or evidence)
	Knowledge translation	Describe how the learning or knowledge generated from this initiative has or will be used
	Measurement	How has or how will this be measured?
		Who is involved in measuring this?
Indicators completed by Editors and/or peer reviewers Editors and peer reviewers assessing the report will need to look for indicators in the following categories	Indicators of involvement	
	Use the STARDIT 'Indicators of involvement' tool	
	Indicators of FAIR	
	Indicators of translation and impact	

360 *The links will be automatically added to the Internet Archive upon submission of the form to
 361 future-proof reports from broken links

362 Table 4: STARDIT – Minimum Contribution Reporting Form (MICRO)

Section	Data category	Data field
Initiative context - This information locates the initiative within a clear context.	Identifying information	Initiative name
		Geographic location or scope
		Purpose of the initiative
		Organisations or other initiatives involved
		Ethics approval (if applicable)
		Funding sources
	Stage or state of initiative	At which stage of the research project has this report been written? (Select from: 1. Before the intervention or initiative– this report is prospective or describes planned activity 2. Ongoing – the intervention or initiative is still taking place 3. After the research project or initiative has occurred
		Methods of the initiative (what is planned to be done, or is being reported as done)
Report authorship – Information about who completed the report and how	Identifying information for each author	Name
		Public domain profiles, institutional pages
		Open Researcher and Contributor ID (orcid.org)
	Accountability	Key contact at initiative for confirming report content
Involvement in initiative Who is involved in this initiative and how? Editors assessing involvement may need to use the STARDIT 'Indicators of involvement' tool	Details about how each group or individual was involved in the initiative	Who was involved (select from groups or submit new group name in free-text)
		Specific tasks of this person or group (list as many as possible)
	Outcomes and outputs	What was the outcome or output of the involvement of these people?
Mapping financial or other 'interests'	Financial or other interests	Describe any financial relationship or other interest this person has to this project
		Describe any conflicting or competing interests
Research data	Hosting and storage	Who is the data from this intervention shared with?
		How is it stored and hosted?
	Dissemination	How is information about this data disseminated?
	FAIR criteria ⁴³	How is/will the data be 'Findable, Accessible, Interoperable, Reusable' according to the FAIR criteria?
Research impacts	Knowledge translation	Describe how the learning or knowledge generated from this initiative has or will be used (including from involving stakeholders)

Discussion

Implementation will need to involve multiple stakeholders, with any useable living-systematic review likely to be at least 5 years away. This paper proposes a starting point only. Decisions about how this project is run, governed and makes decisions will be decided transparently using public online discussion forums, and public events where possible. The data-sharing platform has been designed to be both interoperable with existing standards, and future proofed to allow continuous improvement.

Case studies

The STARDIT data-sharing platform has been designed to align with case study methodology. It allows for having multiple authors in a report, as multiple people involved in this way can bring different ways of analysing and interpreting data^{44,45}. Similarly, having multiple perspectives involved may aid understanding any causal relationships by comparing (triangulating) data from different people, enhancing the reliability of the analysis²⁶. STARDIT provides a way of consistently sharing and comparing data while using the case study method.

Limitations

This paper proposes a model to meet the need for the continued improvement and refinement of the processes, language and taxonomies associated with involving people in planning initiatives and reporting how they were involved³². There is no single process for making decisions of this kind, and the STARDIT project must continually appraise how inclusive the multi-lingual, multi-discipline international model is. The Wikimedia Foundation is a global leader in both refining and improving multi-lingual and international ways of working and this project hopes to continue to work in partnership with 'Science for All' and other organisations to improve these ways of working.

STARDIT aspires to be a usable way for all disciplines to share data about initiatives, however the project requires a critical-mass of adoption in order to generate enough data to be useful. Similarly, the process of creating living systematic reviews from the data is currently theoretical and will require significant development and rigorous testing.

Ensuring that the process is inclusive is paramount to the ensuring that STARDIT is credible. Ensuring that people involved are paid for their time on certain tasks, where possible, will ensure people are not excluded from socio-economic backgrounds where they may not be able to afford to be involved. At the moment STARDIT is relying on people volunteering their time and pro-bono services from not-for-profit organisations. In order for this project to succeed, a more economically sustainable model will need to be co-created transparently, which aligns with the core-values of this project.

STARDIT has been informed by multiple models from around the world, with a number of experts consulted. However, the authors suggest that future versions of STARDIT are informed by regular systematic search, review and appraisal, with the protocol published in PRISMA.

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Mock up of completed Alpha version
Research project context

Identifying information							
Research project name	Geographic location	Purpose of the project	Organisations or initiatives involved	Funding sources	Clinical trial registration details (if applicable)	Relevant URLs/URIs	
Fictional Biobank	UK			Government		Link	Description
						https://www.fictionalbiobank.ac.uk/	Main website
Other relevant information (free text)			This report was co-produced by Chief investigators and participant representatives				

At which stage of the research project has this report been written?		
	Ongoing – the research project is still taking place	

Who completed the report		
Names	Identifying information (public domain profiles, institutional pages)	Open Researcher and Contributor ID (orcid.org)
Jo Bloggs	University.edu/jobloggs	3333333
John Doe	Research participant	
Anonymous	Research participant	

411 Who is involved in this initiative and how?

Who	Specific tasks of this person or group (list as many as possible)	Modes of communication	How were people involved (what methods were used)	Facilitators of involvement	Barriers of involvement	What was the outcome or output of the involvement	Which stage of the research were these people involved?	Cost and time	Learning points	Describe any financial relationship or other interest this person has to this project	Describe any conflicting or competing interests
Data scientists	analysis	Email	Meetings, webinars, conferences	Caffeine	Australian internet speeds	Correlation of DNA sequences and disease risk	Data analysis	400 hours at \$100 an hour	It took more time than expected to plan involving the public	employee	Attended conferences paid for by industry
Members of the public	Improving ethics and governance, overseeing data access	Face to face, email, group video calls	public events, information shared online, formal working groups	1. Paying travel & accommodation 2. Involving potential participants in the design of the involvement plan	Limited budget to pay people for time	Improved ethics and governance framework, acceptable data access policy aligned with perceived public interest	Every stage	10 hours at \$0 an hour. Travel and hotel \$200	Online facilitated discussions were the most efficient way to communicate	Paid for travel, accommodation	Part of advocacy organisation funded by pharma

412 Research data

Who is the data from this initiative shared with?	How is it hosted?	How is information about this data disseminated?
Research institutes which meet ethical criteria	Secure servers	Public events, press releases, social media, conferences
Who is analysing the data?	People from research institutes which meet ethical criteria	
What methods will be used to analyse the data	Specialised programme (link to open source code here)	
Who 'owns' the data	UK Government on behalf of the UK public	
Who controls access to the data	Data Access committee	
How is/will the data be 'Findable, Accessible, Interoperable, Reusable' according to the FAIR criteria?	Link to report here	

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415 Research impacts

What new knowledge has been generated?
Improved understanding of genomic variations which may affect disease risk
Describe how the learning or knowledge generated from this initiative has or will be used
Improved diagnosis for people with rare diseases caused by genomic variations of known significance
How has or how will this be measured?
Reported clinical outcomes
Who is involved in measuring this?
National Health Service England

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417 STARDIT – working proof of concept

418 A working version of the reporting framework can be used at this address:

419 https://en.wikiversity.org/wiki/Template:STARDIT_draft

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STARDIT 'Indicators of involvement' report review tool

For Editors or peer-reviewers reviewing the STARDIT report, it may be necessary to look for objective indicators in the public domain in order to verify reports in categories such as involvement and research data. This section provides a proposed method to transparently review and label involvement.

Background to involvement indicators

Concepts such as 'involvement', 'ethics' and 'democracy' cannot always be expressed fully in linguistic constructs, as they carry resonances of concepts such as equality, justice and human rights⁴⁶. A number of systematic and scoping reviews have attempted to map such concepts^{8,47–49}.

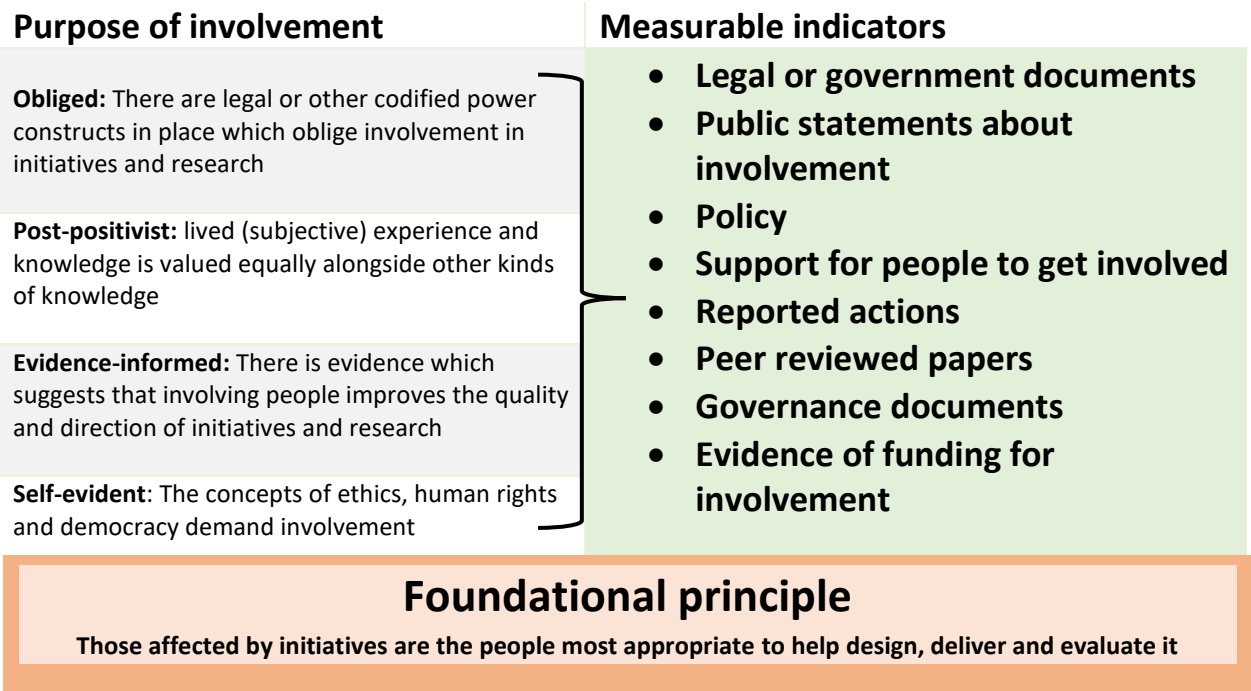
These indicators are an attempt to reduce subjectivity in describing 'involvement' by articulating in a standardised way what objective measures might exist which would suggest that 'involvement' (power sharing) is occurring, and for what purpose^{50,51}. The indicators can be grouped and categorised in the table below and yet all of them rely on a foundational assumption or axiom – which is that those affected by interventions or research are the people most appropriate to design and deliver it – recognising all skills and knowledge have equal value⁵¹. The 'UK Standards for Public Involvement in Research' define indicators of involvement as 'a statement of good practice that describes what is needed to demonstrate meeting the standard'⁵². STARDIT aligns with this terminology, extending 'indicators' beyond public statements in order to incorporate other indicators, for example, governance documents or reported actions.

There may be intrinsic or extrinsic reasons for involving people⁵³. For example, the purpose or 'driver' of involving people might be to include personal experiences in order to improve the research⁵⁴, to abide by regulation or law, or to do it because there is evidence which indicates involving people will improve the research^{55(p356)}. A narrative review identified three broad value systems associated with involving people⁵⁶, which included values based on:

- ethical, human rights, equality, openness and accountability
- evidence based, objective assessments of effectiveness and consequences of involvement

For the purposes of this reporting framework, these have been categorised below as four broad 'purposes' of involvement.

Diagram of the purposes of involvement and measurable indicators



Models and papers which inform the standardised reporting framework

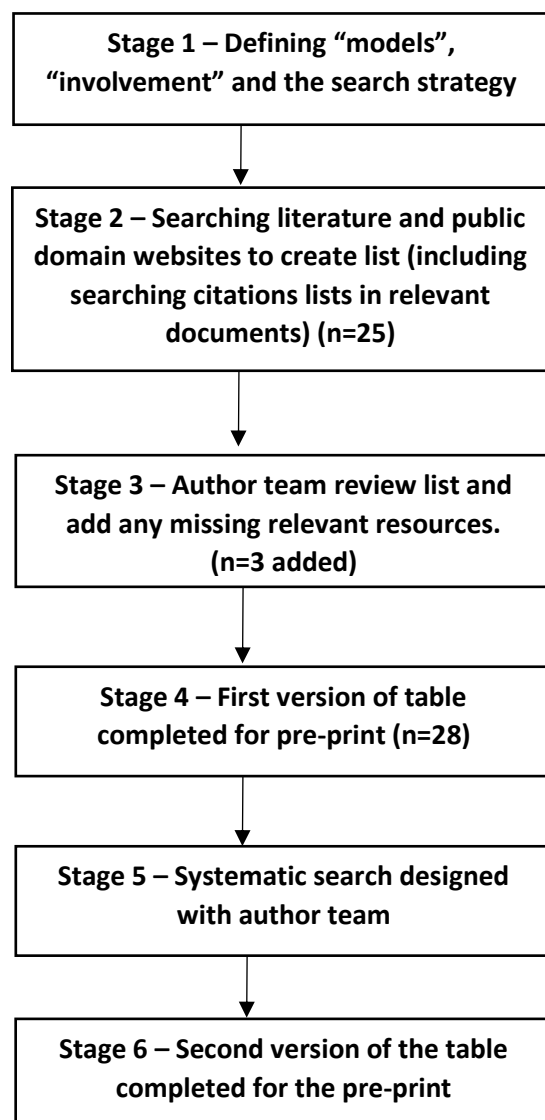
The reporting framework is informed by multiple models and reporting frameworks, will be compatible with many of them and future-proofed to allow further development in the articulation of reporting.

Table 5 summarises the frameworks and models which informed this work and how.

The search strategy is summarised in the figure 'STARDIT models and framework search strategy'.

In order to inform future iterations, the authors suggest that future versions of STARDIT are informed by regular systematic search, review and appraisal , with the protocol published in PRISMA.

Figure 5: STARDIT models and framework search strategy



472 Table 5: Models and frameworks which inform the standardised reporting framework

Name	Status	Access	Year	Field	Aspects which informed STARDIT
7Ps Model ⁵⁸	Peer-reviewed	Paywall access	2012	Health research and policy	General terminology, taxonomy for stages of research adapted from this model
ACTIVE framework to describe stakeholder involvement in systematic reviews ⁷⁷	Peer-reviewed	Paywall access	2019	Systematic reviews in health research	Informed terminology around defining stakeholders and ways of defining involvement
Australian Research Council - Engagement and Impact Assessment ⁷⁰	Not peer-reviewed	Public domain website	2018	Research (multi-disciplinary)*	Informed general terminology, including assessing involvement and impact
Bloom ⁹⁴	Peer-reviewed	Open access	2018	Clinical Trials	Informed language to describe partnerships between different stakeholder groups (industry, academia, patients and public)
BMJ guidelines for reporting patient and public involvement in research ⁷⁵	Not peer-reviewed	Public domain website	2019	Medical research	Informed minimum reporting requirements for STARDIT, informed 'cost' and 'time' reporting
Brett ^{10,31}	Peer-reviewed	Open access	2014	Health and social care research	Informed general terminology, methods of assessing impact and informed search strategy
Carman ⁹⁰	Peer-reviewed	Open access	2013	Health care, population health	Informed general terminology, including different descriptions of involvement and enabling conditions that support it
Center for Comparative Effectiveness Research in Cancer Genomics ⁶⁰	Peer-reviewed	Paywall access	2012	Cancer Genomics	Informed general terminology and terminology specific to genomics research, as well as methods of assessing impact of involving stakeholders.
Cochrane Knowledge Translation Strategy ⁶¹	Not peer-reviewed	Public domain website	2017	Health research evidence, knowledge translation	General terminology, including 'audiences' and ways of assessing knowledge translation
CONSORT for randomised controlled trials ⁶⁵	Peer-reviewed	Open access	2010	Randomised controlled trials	General terminology, including stages of trials, outcome reporting and other categories.

CRedit taxonomy ⁶³	Not peer-reviewed	Public domain website	2017	Biology	Informed taxonomy to define author contributions to primary research papers
Dissemination and Implementation Toolkit (PCORI) ⁹¹	Not peer-reviewed	Public domain website	2017	Health care	Informed terminology and assessment of involvement at the stages of dissemination and implementation
Domecq ⁹⁵	Peer-reviewed	Open access	2014	Healthcare research	Informed general terminology, informed search strategy
Dubois ⁹³	Peer-reviewed	Open access	2013	Medicine comparative effectiveness research	Informed terminology around involving people in assessing evidence adoption
Dukhani ³⁶	Peer-reviewed	Open access	2018	Health care	Informed general terminology, search strategy, articulating outcome measures
EQUATOR guidelines ⁶⁸	Not peer-reviewed	Public domain website	2019	Health research	Informed general terminology, informed design of reporting 'explicit methodology', STARDIT designed to work with all EQUATOR guidelines.
EQUATOR method for developing reporting guidelines ⁶⁹	Peer-reviewed	Open access	2010	Health research	Informed general terminology, informed the design of the process for co-creating STARDIT
European Patients Academy on Therapeutic Innovation (EUPATI) Guidelines on Patient Involvement in Research and Development ⁷⁹	Peer-reviewed	Open access	2018	Medicine research and development	Informed general terminology, including stages aligned to guidelines
FAIR Guiding Principles for scientific data management and stewardship ⁴³	Peer-reviewed	Open access	2016	Scholarly data (multi-disciplinary)	Alignment with categories for reporting on principles for scientific data
Fazey ³²	Peer-reviewed	Paywall access	2014	Interdisciplinary and multi-stakeholder research	Informed terminology regarding knowledge exchange in interdisciplinary and multi-stakeholder research
GRIPP2 ⁵⁷	Peer-reviewed	Open access	2017	Health research	Terminology, ways of reporting involvement and impact, mapping preferences for involvement

Guidance on co-producing a research project (INVOLVE) ⁸⁵	Not peer-reviewed	Public domain website	2018	Health and social research	Informed general terminology, how people can be involved in stages of research
International Committee of Medical Journal Editors (defining the role of authors and contributors) ⁷⁴	Not peer-reviewed	Public domain website	2019	Medical journal publication	Informed terminology defining 'authorship', including authors of STARDIT reports
National Standards for Public Involvement in Research ⁵²	Not peer-reviewed	Public domain website	2018	Health research	General terminology, indicators of involvement (including impact)
NIHR Public Involvement Impact Working Group ⁸⁴	Not peer-reviewed	Public domain website	2019	Health research	Informed definitions of impact
Nilsen ⁹⁶	Peer-reviewed	Open access	2006	Health care	Informed general terminology, informed search strategy
Nunn ⁸	Peer-reviewed	Open access	2019	Public health genomics	Informed general terminology, informed task-based reporting categories.
Open Toolkit for Tracking Open Science Partnership Implementation and Impact ⁷⁸	Awaiting-peer review (as of July 2019)	Open access	2019	Science (multi-disciplinary)	Informed terminology and data collection fields
Patient engagement (Canadian Institutes of Health Research) ⁹²	Not peer-reviewed	Public domain website	2017	Health research	Informed general terminology around involving people in health research
Patient Engagement Quality Guidance ⁸⁸	Not peer-reviewed	Public domain website	2018	Medicine development	Informed general terminology, including assessing involvement in the stages of medicine development
Patient Focused Medicines Development (PFMD) 'Book of Good Practices' ⁷³	Not peer-reviewed	Public domain website	2018	Medicines research	Informed general terminology, terminology around shared 'purpose' and data collection fields – in particular the 'Patient Engagement Quality Guidance Tool' (' Planning a project ' and ' Assessing an ongoing or completed project ')

PCORI ⁵⁹	Not peer-reviewed	Public domain website	2018	Healthcare research	Informed general terminology within the word 'stakeholder'
Pollock ⁸¹	Peer-reviewed	Open access	2018	Systematic reviews in health research	Informed general terminology, informed design of STARDIT creation process
PPI Ready: Researcher Planning Canvas ⁸⁰	Peer-reviewed	Open access	2019	Basic and preclinical health research	Informed general terminology, including impact and values
PRISMA for systematic reviews ⁶⁴	Peer-reviewed	Open access	2009	Systematic Reviews	General terminology, including stages of systematic reviews
PROGRESS-Plus ⁸²	Multiple peer-reviewed papers cited	Public domain website	2017	Systematic reviews in health research	Informed 'Other information' in describing authors categories and 'barriers' (describing potential equity issues for who was involved)
Public Involvement (Health Research Authority) ¹⁹	Not peer-reviewed	Public domain website	2019	Health research	Informed general terminology, including distinctions between involvement and engagement
Public Involvement Impact Assessment Framework ⁶⁶	Not peer-reviewed	Public domain website	2014	Health research	General terminology, mapping values and preferences associated with involvement, assessing impacts of involvement
Reed ³⁹	Peer-reviewed	Open access	2018	Evaluating involvement in interdisciplinary research	Informed general terminology, informed ways of evaluating involvement in research and other data collection
Research Activity Identifier (RAiD) ⁷²	Not peer-reviewed	Public domain website	2018	Research (multi-disciplinary)	STARDIT designed to be interoperable with RAiD
Shippee ⁶⁷	Peer-reviewed	Open access	2013	Biomedical and health services research	General terminology, description of research stages, informed search strategies
Social Determinants of Health (World Health Organisation) ⁸³	Published book (WHO)	Open access	2003	International public health	Informed 'Other information' in describing authors categories and 'barriers' (describing potential equity issues for who was involved)

Supporting the Use of Research Evidence (SURE) ⁷⁶	Not peer-reviewed	Public domain website	2011	Evidence-informed policy	Informed terminology to describe evidence-informed policy, informed terminology to describe stakeholders
Tackling Representativeness: A Roadmap and Rubric ⁸⁶	Not peer-reviewed	Public domain website	2018	Health care	Informed terminology around representation
The book of good practices in Patient Engagement ⁸⁷	Not peer-reviewed	Public domain website	2018	Medicine development	Informed general terminology, including defining stakeholders and stages of medicine development
The Value of Engagement (PCORI) ⁸⁹	Not peer-reviewed	Public domain website	2018	Health care	Informed general terminology, concepts of 'engagement' and 'involvement' and partnerships and evidence informed involvement
The Value+ Toolkit (European Patients' forum) ⁷¹	Not peer-reviewed	Public domain website	2013	Health research and services	Informed general terminology, informed definitions of involvement and indicators of involvement and barriers to involvement. STARDIT designed to align with Value+ Toolkit
Tugwell 6Ps ⁶²	Peer-reviewed	Open access	2006	Health research evidence, knowledge translation	General terminology, ways of assessing facilitators and barriers (including 'community' involvement), ways of involving people in co-designing research
United Nations Evaluation Group (UNEG) ⁹⁷	Not peer-reviewed	Public domain website	2013	Evaluation of functions and products of UN entities	Impact evaluation informed by 'Impact Evaluation Guidance Document'

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474 *This impact assessment has been piloted with the following kinds of research; Chemical Sciences, Medical and Health Sciences, History and Archaeology,
475 and Philosophy and Religious Studies, Environmental Sciences, Agricultural and Veterinary Sciences, Engineering, Education, Studies in Creative Arts and
476 Writing, Language Communication and Culture, and Indigenous research.⁷⁰

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